# INOVA Fairfax Hospital Transplant Center

# Post-Transplant Manual



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# **Inova Fairfax Hospital Transplant Center**

Office Hours: 8:00 am - 4:00 pm, Monday - Friday

Address: Inova Transplant Center

3300 Gallows Road Falls Church, VA, 22042

**Scheduling:** (703) 776-2986 or (703) 776-8047

(7:00 am - 4:00 pm)

**Administrative Support:** (703) 776-2986

Fax: 703-776-8046

**Physicians:** Johann Jonsson, M.D., F.A.C.S.

James Piper, MD Ravinder Wali, MD Eric Siskind, MD

**Director of Abdominal Transplant**Nikki Gage RN, BSN, CCTC

**Pre Transplant Coordinators:**Bonnie Erickson, BSN, RN CCTC

Grace Capuno, BSN, RN

Waleska Sing, RN MSN CCRN FNP-BC

Ann Bigger, RN, NP

In Hospital Midlevel Providers: Amanda Lalicato, NP

Rosalyn Mason, PA

Post-Transplant Coordinators: Jacquelyn Vaughan, BSN, RN, CCTC

Neng Alim, RN, BSN Rachel Lambert, RN, BSN

Amy Thatcher, NP

**Transplant Social Workers:** Meg Bunker, LCSW

Leslie Pionke, LCSW

**Transplant Pharmacist** Chika Onwudiwe Pharm.D.

Transplant Dietitians Lauren Thornton, MS, RD

Mary Ellen Sabatella, MS, RD



**24-Hour Emergency Telephone:** (703) 776-4001

Ask operator to page coordinator on call for Abdominal (Kidney/Pancreas) Transplant.

**Items to bring to first clinic visit:** Education notebook

Medications Medication list

Blood pressure cuff (if instructed)

**Bring to each clinic visit:** Education notebook

Pharmacy Refill Line: (703) 776-2986

Press 4, then press 3, then press 6

Leave message with: First and last name Date of birth Medication name

Pharmacy name and number

#### **Urgent Problems/ Emergencies:** For *urgent* issues after hours.

Call the hospital operator at (703) 776-4001. They will contact the on-call coordinator. When the on-call coordinator calls, he/she will need to know your concern(s) and specific details including vital signs (temperature, blood pressure and pulse) and symptoms. Be prepared to discuss any recent rejection or infection episodes, the treatment given, how long ago, and onset of this new set of symptoms. **If you do not receive a return call within 30 minutes, please call the hospital operator again.** 

**Non-Urgent problems:** If you have a non-urgent issue, call your coordinator directly. If he/she does not answer, please leave a message and we will make every attempt to get back to you. Remember that the coordinators are available Monday thru Friday 8:00 am - 4:30 pm

**Medications Renewals:** If you need medications refilled please call (703) 776-2986. The line will be checked every 48 hours. Please leave your name, date of birth and a call back number. Also, leave the name of the medication, dosage, and frequency you are taking the medications as well as your pharmacy of choice and their phone number.

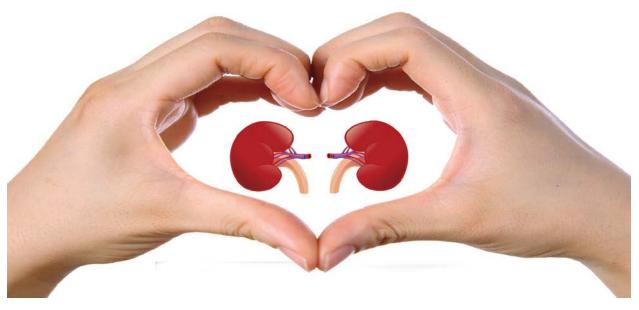


# **Guidelines to Caring For Your New Kidney**

Now that you have received a new kidney and are about to go home, it is important to understand that having a new kidney brings many new responsibilities.

Your transplant team will continue your kidney care. At this point, though, the most important member of the team is YOU! Without your active support, the team's best efforts cannot succeed. For lifetime care of your new kidney you will need to:

- 1) Follow your medication schedule as instructed
- 2) Make sure you have healthy daily habits that include a healthy diet and regular exercise. Visit the dentist every six months.
- 3) Check and record your weight, temperature, blood pressure and pulse as directed by the team.
- 4) Communicate with your transplant team regularly especially if there has been a significant change to your health.
- 5) Keep all scheduled follow up and lab appointments.
- 6) Make sure all your doctors, your dentist and your pharmacist know about your medications and your care.





# **Post-Transplant Clinic**

**Clinic Hours** 

Monday 8:00-12:00

Tuesday 8:00-12:00

Thursday 8:00-12:00

- Please bring your daily record sheet including; temperature log, blood sugars, weight, blood pressure, and any other information you have been recording. Also, bring your transplant manual with you to each visit.
- At your visit, you will be weighed, blood pressure checked, and your blood drawn.
- Any problems or concerns that you have will be discussed with your transplant team.
- **<u>DO NOT TAKE</u>** your morning dose of Tacrolimus, Sirolimus and/or Cyclosporine, until after your blood is drawn. Transplant blood draws should be completed no later than 10:30a.m.
- <u>ALWAYS BRING</u> your morning dose of Tacrolimus, Cyclosporine, and/or Sirolimus with you to the clinic to take **AFTER** blood work is drawn.
- It is *strongly* recommended that you carry an updated list of ALL of your medications. This list should include the name, dosage and frequency of each medication you take (Example: Tacrolimus 2mg by mouth every 12 hours).
- Your physician will examine you, ask questions about your health at home, review your medications, labs and answer any questions you might have.



# Post Kidney and Kidney/Pancreas Follow-Up Clinic and Lab Work Visits

Clinic begins at 8 am and lab opens at 7 am. The clinic is located at Fairfax Hospital in the Heart and Vascular Institute. Always bring your picture ID, insurance cards and this transplant manual.

Week 1	Two Clinic Visits*
Week 2	One Clinic/Lab visit*
Week 3	One Clinic Visit*
Week 4	One Clinic Visit*
Weeks 6, 8, 10, 12	One Clinic Visit*

You must have lab work completed one week prior to your scheduled appointment for appointments that are past 12 weeks. Ask your coordinator for a lab prescription.

At the end of 3 months, you will be referred to your primary nephrologist; they will see you monthly for the first year, except for your 6, 9 and 12 month visits at the INOVA Transplant Center.

Months 6, 9, 12	Clinic Visit*
Month 18	Clinic Visit*
Month 24	Clinic Visit*
After month 24, (2-year visit)	Yearly lab/clinic visit during the anniversary month of your transplant.

<sup>\*</sup>The above schedule may vary at the discretion of your physician.

Clinic visits and lab visits must be scheduled through the Abdominal Transplant scheduling secretary at (703) 776-8047.



# What to Monitor at Home

You will be asked to monitor the following:

#### 1. **Temperature:**



- a) We ask that you take your temperature two times per day before breakfast and dinner. Please record the results on your patient record sheet.
- b) Also, take your temperature anytime you feel chilled, hot or achy. This may be the first sign of infection/rejection.
- c) Please contact the transplant team for any temperature greater that  $100^{\rm o}\,{\rm F.}$

#### 2. **Blood Pressure:**



- a) You will receive or be asked to purchase a blood pressure machine before you are discharged from the hospital. Your nurse will teach you and your family how to use the blood pressure machine.
- b) We ask that you take your blood pressure in the morning before breakfast and again in the evening before dinner. Please record the results on your patient record sheet.
  - \* You should notify the transplant team if your blood pressure is:

Systolic (Top number) greater than 180 or less than 100 Diastolic (Bottom number) greater than 100 or less than 50

\*Your blood pressure machine will also give you your pulse. You should notify the transplant team when your pulse is:

Greater than 120 or less than 50



#### 3. Weight:



- a) Please weigh yourself every morning after you urinate, but before you eat and record the results on your patient record sheet.
- b) You should notify your transplant team for any weight gain greater than 3 lbs. in a 24 hr. period.

#### 4. Urine output:



- a) You will be asked to measure your urine output and fluid intake and record the totals for a 24 hour period on your patient record sheet.
- b) It is extremely important to keep yourself well hydrated by drinking at least 2 liters (2000mL) of fluid every day.
- c) Please notify the transplant team for any decrease in urine output over a 24 hour period.

#### 5. **Blood Sugars:**



- a) If you were diabetic before transplant or have recently developed diabetes since transplant, you will be asked to monitor your blood sugar. Please check your blood sugar before each meal and at bedtime. Record the results on your patient record sheet. You may be required to check your blood sugar more frequently based on your disease.
- b) You should notify the transplant team or your endocrinologist (blood sugar doctor) for blood sugars less than 80 or greater than 350.



# **Activity Following Transplant**

After transplant it is recommended you participate in a regular exercise plan. Exercise can help control weight gain, decrease blood pressure, lower cholesterol, increase energy, improve digestion, improve sleep, reduce stress, and improve self-esteem.

Walking is one of the best forms of exercise. Anyone can participate in this activity at no cost. We encourage you to start exercising within the first 2 to 4 weeks following your transplant. Discuss any exercise program with your Transplant Coordinator and Physician.

#### **Restrictions after Transplant**

• No lifting greater than 10 lbs. for the first 6-8 weeks post-transplant. No sit-ups, Pilates or other core exercises for the first 6 months post-transplant. These activities can lead to a hernia (weakness in the abdominal wall at the site of the incision), if started too early. This could lead to additional surgery.

#### Driving, Returning, to Work/School

- You will need to get permission from your Transplant Physician to return to work and driving. This will depend on your recovery. The length of recovery is individualized.
- The usual time for returning to work is 4-8 weeks.
- The usual time for returning to driving is 4 weeks. For your safety and safety of others you should not drive while still taking narcotics for pain.

#### **Sexual Activity**

- Sexual activity is a normal part of a person's life. You can begin having sexual intercourse whenever you feel up to it. Most clinician's suggest waiting 3-4 weeks; however you know your body best!
- Women: Should not become pregnant until after the first year of your transplant and only after consulting with your Transplant Physician. If you



are planning to become pregnant, notify the Transplant Team, Nephrologists and OB/GYN Physician immediately because some of your medications can cause birth defects.

• Men: May experience impotency due to the medications. If this occurs, please discuss it with your Physician. If you are planning on having children, you should discuss this with the Transplant Team as some medications could negatively impact fertility.

#### **Acceptable forms of birth control**

- Diaphragm (properly fitted by Gynecologist)
- Condom with spermicide
- Birth control pills or Depo-Provera injection these may or may not be recommended depending on your medical history. Ask you Transplant Team and your Gynecologist.
- IUD's ARE NOT recommended because of their risk of infection

\* Do not be embarrassed to ask your transplant team about sexual activity. We are here to help you return to good physical and mental health.

#### **High Blood Pressure**

High blood pressure is a common problem after transplant. Some of the
medications you take can cause an increase in blood pressure. An increase
in weight can also cause an increase in blood pressure. You will be
monitoring and recording your blood pressure at home. These recordings
will be reviewed in the transplant clinic. You may be required to take
medication or reduce your salt intake to keep your blood pressure under
control.

#### **Skin and Hair**

• Prednisone and other medications cause transplant recipients to have an increased risk for skin cancers. **Avoid extensive exposure and wear sunscreen lotion of at least SPF 30 while outside.** Remember sunscreens wear off with swimming and sweat. You may have to re-apply often. An



important for you to see a dermatologist at least once a year to monitor for and treat skin cancer.

- Prednisone can cause acne on your face, shoulders, chest, or back. If you develop acne it is recommended that you wash the affected area three times per day with a mild skin cleanser.
- Dry skin can also become a problem for some transplant recipients. Use mild soap and apply body lotion after bathing.
- Minor cuts and scrapes should be washed with soap and water daily. An anti-biotic ointment may be applied with clean bandage. Report any redness, swelling, or drainage to your transplant team immediately.
- Prednisone can affect the condition of your hair. Perms, permanent hair dye, tints, and bleach make hair brittle and break off. Use a good conditioner and inform your hairdresser you are on medication that can affect the condition your hair.

#### Alcohol

• Do NOT drink alcoholic beverages. Alcohol and some of your medications are broken down by the liver. Mixing alcohol and your medications can lead to liver damage. Medications broken down by your liver include; Tacrolimus, Cyclosporine, Sirolimus and Everolimus.

#### **Smoking**

• It has been determined by the Surgeon General that smoking is harmful to your health. DO NOT smoke after transplant. If you already smoke, it is strongly recommended that you stop smoking.

#### **Dental Care**

- Regular and routine dental care is important.
- Before any dental procedure or cleaning you may need antibiotics. Contact your Transplant Team in advance.



#### **Immunizations and Shots**

The transplant ream recommends:

- > Flu shot every year
- > Pneumovax every 5 years
- > Tetanus every 10 years

If you are traveling out of the country and need vaccines or pre-medications please discuss it with your Transplant Team <u>in advance</u> so that they can connect you with an Infectious Disease Physician.

You are NOT allowed vaccinations that contain LIVE virus, including FLU-MIST nasal spray vaccine and the Shingles vaccine.



# **Support**

Receiving a transplant can be an overwhelming experience. Keeping your new organ is a LIFETIME commitment. **You are not alone!** 

Our transplant social workers are here as a resource for you. They can help you navigate through this time of transition and if they cannot help you directly, can point you in the RIGHT direction. Please remember that transplant is a lifestyle change and as with any change, there is an adjustment period.

#### Please contact your social worker if you have any issues with:

- Changes in mental health
- Changes in level of coping after transplant
- Changes in level of family/social support
- Changes in ability to obtain your transplant medications
- Change in insurance coverage status
- Inability to keep transplant clinic appointments and/or get needed lab tests
- Any other concerns that need to be addressed

The INOVA transplant center also has a monthly support group for post-transplant patients. It is held on the 2<sup>nd</sup> Tuesday of every month.

You can contact a transplant social worker for assistance or for more information about the support group M-F during business hours.

Meg Bunker, LCSW (703) 776-6140

Leslie Pionke, LCSW (703) 776-6096





# **Healthcare Recommendations**

#### **General Health Care:**

- After your transplant you should see your primary care physician for your routine medical care.
- You should complete a physical every year with your primary care physician.
- All transplant patients should do a monthly breast or testicular exam.
- The transplant experience may affect your feelings and moods. Depression is common. If you need help coping with your feelings, discuss this with your Transplant Team.
- Get enough rest and have proper nutrition to help you fight off infections
- See your dentist at least every six months. Remember to contact the Transplant Team or your physician for additional medications (antibiotics) prior to dental visits.

#### **Nutrition:**

- Eat a well-balanced diet
- Smaller more frequent meals may be necessary if there are feelings of fullness or nausea.
- Food may taste differently due to medications. Experiment with spices and flavoring.
- A "no added salt" diet is recommended for most people

Good nutrition is an important part of the recovery process. A common problem after transplant is **WEIGHT GAIN**. Your appetite may be improved and now you will be able to eat foods that were restricted while on dialysis. Moderation is the key to your eating habits after a transplant. We have a dietitian on staff to help you develop a specific individual nutritional plan if needed.





# **Ureteral Stent for Kidney Transplant Patients**

During the kidney transplant procedure, a thin stent is placed in the ureter. This is between your bladder and your new kidney.

The purpose of the stent is to keep the ureter open while the sutures are healing. The ureters are very small and can collapse without the support of the stent.

Generally, most patients do not notice the stent. Sometimes patients may have blood in their urine that may come and go.

This stent needs to be removed by a Urologist around 4 weeks post-transplant. It is a very quick procedure and generally done in the physician's office with local anesthetic. Your Coordinator will discuss this with you in more detail. Below is the approximate date when the stent should be removed.

Kidney Transplant Date:	
4 Weeks Post-Transplant:	
(Stent Removal)	

Below is a partial list of Urologists with offices that are close to Inova Fairfax Hospital. A full list of Urologists can be found on the Inova web site or through your insurance company. Feel free to choose whichever Urologist your insurance covers to remove your stent.

#### **Urologists:**

IMG (Inova) Urology 8503 Arlington Blvd. Suite 310 Fairfax, Va. 2203 Phone (703) 208-4200

Nabil Khawand, M.D. 106 Irving St. NW #3500 Washington, D.C. 20010 Phone (202) 882-3736 Commonwealth Urology 3020 Haymaker Court Suite B-111 Fairfax, VA 22031 Phone (703) 876-0288

Todd Tescher, M.D. 8316 Arlington Blvd. Suite 514 Fairfax, Virginia 22031 Phone (703) 289-4600



# **Insurance Information**

It is important that you become familiar with the benefits of your insurance. Transplantation is costly. These costs continue after surgery and hospitalization for the transplant. The better you understand your insurance and out-of-pocket expenses, the easier the transition to your new life.

- Medications can be the most expensive part of the post-transplant phase. It is important that you know how much your insurance company is going to pay towards your medications. If you find you are not able to afford your medications contact your transplant social worker immediately.
- It is very important that you notify the financial coordinator if you are thinking about changing your insurance coverage or if it has changed. Our financial coordinators are available to discuss your financial and insurance issues. They are available to help you decide if changing insurance policies is the best option for you. We want to *help* you make the best choice.
- Most kidney transplant patients are entitled to Medicare for three years. If you are transplanted before you start dialysis, paper work must be filled out for you to apply for Medicare. We will help you fill out these forms. It is important that these forms are filled out and taken to your local Social Security Office as soon as possible.
- Some insurance policies require you to bring a PCP referral for all clinic and lab work visits. The financial coordinators will check with your insurance company to see if a referral is required. It is your responsibility to obtain this referral before your visit. If you arrive to the clinic without a referral, you may not be seen and this may delay your care.
- Some insurance companies require a specific lab to be used after surgery. We can assist you with this information. It is your primary responsibility to inform us of any changes to your lab provider.



Week of							
	MON	TUE	WED	THUR	FRI	SAT	SUN
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Temperature Before Dinner							
Weight Before Breakfast							
Morning  Blood Pressure							
24 - Hour Urine output							
24 - Hour Fluid Intake							
Blood Sugars							
Other							

Questions/Concerns for my transplant team:	
, ,	



Week of							
	MON	TUE	WED	THUR	FRI	SAT	SUN
Temperature Before Breakfast							
Temperature Before Dinner							
Weight Before Breakfast							
Morning Blood							
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24 - Hour Urine output							
24 - Hour Fluid Intake							
Blood Sugars							
Other							

Questions/Concerns for my transplant team:	
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Week of							
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Temperature Before Dinner							
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Blood Pressure							
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Questions/Concerns for my transplant team:



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Questions/Concerns for my transplant team:	



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Questions/Concerns for my transplant team:	
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24 - Hour Fluid Intake							
Blood Sugars							
Other							

Questions/Concerns for my transplant team:	



# **General Medication Information**

The medications that you need to take to care for your transplant may seem overwhelming at first. Please refer to the guidelines on the following pages to help assist you in understanding your medication regime including; Do's and Don'ts, managing medication schedule, food and immunosuppression and a medication guide.

# Do:

- 1. Take all of your medicines as directed by your Physician.
- 2. Store medications in a cool, dry place away from heat and humidity.
- 3. Learn both the brand and generic names of each medication you are taking and why you are taking it.
- 4. Report all side effects to your Transplant Coordinator or Physician.
- 5. Keep medications out of reach of small children.
- 6. Keep a list of your medications with you at all times.
- 7. Wear sun block of SPF 30 or greater while outside.

# Don't:

- 1. Change or skip a medicine unless directed to do so by a member of your Transplant Team. If you miss a dose, DO NOT double the next dose; contact your Transplant Physician or Transplant Coordinator immediately.
- 2. Take any other medications, over-the-counter or prescribed, unless directed to by your Transplant Physician or Transplant Coordinator. If a non-transplant Physician orders medication, check with the Transplant Team before you take it. Some medicines and herbs might cause damage to your transplant or interact with your anti-rejections drugs so that they become less effective. Many common medicines cause problems in transplant patients.

#### These include:

- Non-steroidal anti-inflammatory drugs (NSAIDs), such as ibuprofen (brand name Motrin, Advil, Aleve) or naproxen.
- Also, some antibiotics can drastically alter the level of some anti-rejection. medicines.



# **Medication Management**

It helps to develop a system to keep track of your medication. There's no right or wrong way to manage your medicines. You just need to develop a system that works for you. You also need to remember that your medicines and doses will be changing during the first year. So you need a way to keep track of all your medicine changes. Here are a few ideas:

#### Plastic pill dispensers

Organize your medicines according to the date and time you need to take them. If you are going to buy a pillbox, look for one that is organized by the days of the week with slots for different times of the day. These let you see what medications you need to take throughout the day.

#### Chart

Will tell you what medications to take and when to take them. If you use a chart, be sure you can make changes to it easily. Remember, your transplant physicians will be changing your medicines frequently, so you will need to adjust your medicine chart.

#### Phone/Watch with a timer

Set an alarm/alert to help you remember when to take your medications.

Some patients set up a routine to help them. For instance, they always take their morning medicines after they eat breakfast and their nighttime pills after they brush their teeth.

It is a good idea to bring paper and pen to clinic so you can make notes about any medicine changes.





# **Immunosuppression and Food**

- Tacrolimus, Cyclosporine, and Prednisone can increase you <u>blood sugar</u>. Some individuals will become diabetic once they are on these medications.
- If you are already a diabetic on insulin, your insulin requirements may increase. If you are a diabetic on oral medications or diet control, there is a good possibility you will require insulin after transplant.
- If you have a strong family history or are overweight, you will also have an increased risk of developing diabetes after transplant.

#### **Symptoms of diabetes include:**

Increased thirst
Increased frequency of urination
Blurred vision
Confusion

Please notify the Transplant Team Immediately if you experience any of these signs or symptoms

- After transplant you will have normal kidney function and will no longer be
  restricted in regards to your <u>phosphorus</u> intake. You are encouraged to drink milk
  and eat dairy products to increase you phosphorus intake. Some individuals may
  require a phosphorus supplement.
- Tacrolimus and Cyclosporine can *increase* your <u>potassium</u>. Some individuals will be required to monitor their potassium intake. Some individuals will also require medications to keep their potassium normal (see next page for foods high in potassium).
- Tacrolimus and Cyclosporine can *lower* your <u>magnesium</u>. Some individuals will be required to take magnesium supplements after transplant.
- Wash your fruits and vegetables well.
- Avoid grapefruit as it may interact/interfere with your medications.
- <u>DO NOT</u> eat raw or undercooked meat, poultry, or fish. Remember to measure cooking temperatures.



# Foods high in Potassium

## **Fruits**

### **Apricots** Avocado Banana Cantaloupe **Dates Dried Fruits** Elderberries Figs Guava Honeydew Kiwi Mango **Nectarines** Orange Orange Juice Papaya **Passion Fruit Juice** Pomegranate Prunes Prune Juice Raisins **Tangerine**

# Vegetables

Artichokes Beans (all) Carrot Juice **Brussel Sprouts** Falafel Lentils Okra Split Peas Black-Eyed Peas Potatoes (all) Pumpkin Soybeans Spinach Squash (all) **Tomatoes** Tomato Juice/Sauce Vegetable Juice Yams

## Other

All bran cereals
Ketchup
Cereal with Fruit/Nuts
Chocolate Milk
Coffee (limit 2 cups)
Hot Chocolate
Instant Breakfast
International Coffee
Molasses
Nuts (limit 2 oz.)
Peanut butter (limit 2 oz.)
Salt Substitute
Soy Flour
Wheat Bran
Wheat Germ





Tacrolimus (brand name: Prog	graf <sup>TM</sup> )
Why do I need to take this drug?	To prevent rejection
How should I take this drug?	Prograf comes in different strengths:  • 0.5 mg capsule  • 1 mg capsule  • 5 mg capsule  Your doctor will decide the best dose for you.  Take Prograf <i>two times</i> a day: Once in the morning and again 12 hours later.  Example: Take a dose at 9am; take another dose at 9pm.  Take the pills at the same time each day. If you miss a dose, take the next dose when scheduled. Do not take a double dose.  On clinic days wait to take your morning dose until after you have your blood drawn. Do this even if it means taking the drug later than usual. You will need to bring this medicine to clinic with you and take after labs are drawn.
What side effects can this drug cause?	<ul> <li>Increased blood sugar, diabetes</li> <li>Headaches, tremors</li> <li>High blood pressure</li> <li>An increased risk of infection</li> <li>An increase in your potassium level</li> <li>Decreased kidney function</li> </ul>
Is there anything else I should know?	When taking this medicine avoid eating grapefruit or drinking grapefruit juice (including sodas with grapefruit – Fresca, Citrus Blast)  If you miss a dose take it as soon as you can. If it is almost time for your next dose do not take your missed dose. Do not take double or extra doses.



# Cyclosporine

 $(\text{brand name: } Neoral^{TM})$ 



	£2002 COM
Why do I need to take this drug?	To prevent rejection
How should I take this drug?	Cyclosporine comes in different forms/strengths:  • 100 mg capsule • 25 mg capsule • liquid form  Your doctor will decide the best dose for you.  Take Cyclosporine <i>two times</i> a day: Once in the morning and again 12 hours later.  Example: Take a dose at 9am; take another dose at 9pm.  Take the pills at the same time each day. If you miss a dose, take the next dose when scheduled. Do not take a double dose.  On clinic days wait to take your morning dose until after you have your blood drawn. Do this even if it means taking the drug later than usual. You will need to bring this medicine to clinic with you.
What side effects can this drug cause?	<ul> <li>Increased hair growth</li> <li>Redness, soreness or growth of the gums</li> <li>Slight shaking of the hands</li> <li>High blood pressure</li> <li>Acne</li> <li>A burning to tingling feeling in the joints or limbs that comes and goes</li> <li>Decreased kidney function</li> </ul>
Is there anything else I should know?	When taking this medicine avoid eating grapefruit or drinking grapefruit juice (including sodas with grapefruit – Fresca, Citrus Blast).  Different preparations of cyclosporine are absorbed at different rates which will affect the amount of medicine in your blood. To avoid having a too high or too low level of cyclosporine in your blood, always check that you were given the brand of cyclosporine that you were prescribed. Do not change brands without checking with your post-transplant nurse.



# **Belatacept**

 $(\text{brand name: } Nulojix^{TM})$ 



Why do I need to take this drug?	To prevent rejection
How should I take this drug?	This medication is only available as intravenous (IV) medication. Initially it will be given twice weekly, but eventually it will be given once each month.
What side effects can this drug cause?	<ul> <li>Vomiting, abdominal pain</li> <li>Joint pain</li> <li>Cough</li> <li>Low blood pressure</li> </ul>
Is there anything else I should know?	This is a lifelong medication that needs to be given by IV.  You will need to have a visiting nurse arranged or go to an infusion clinic in order to have your monthly dose given.



#### Mycophenolate mofetil $(\text{brand name: } CellCept^{TM})$ Why do I need to To prevent rejection take this drug? How should I take CellCept comes in different strengths: this drug? 250 mg capsule 500 mg tablet Your doctor will decide the best dose for you. Take CellCept *two times* daily: once in the morning and again 12 hours later in the evening. **Example:** Take a dose at 9am; take another dose at 9pm. Take the pills at the same time each day. If you miss a dose, take the next dose when it is scheduled. Do not take a double dose. What side effects Diarrhea can this drug • Nausea, upset stomach, vomiting cause? A decrease in your white blood cell count and platelets An increased risk of infection. Do not crush, or split the tablets. Do not open the capsules. Avoid Is there anything else I should touching the pill's powder. If you touch the powder wash your hands well know? with soap and water. If you are not able to swallow the tablets or capsules, let your doctor know. There is a liquid form that is available. Do not take any antacids (such as Maalox or Mylanta) at the same time you take CellCept.



#### Mycophenolate sodium $( \text{brand name: } Myfortic^{TM}) \\$ Why do I need to To prevent rejection take this drug? How should I take Myfortic comes in different strengths: this drug? 180 mg tablet 360 mg tablet Your doctor will decide the best dose for you. It is best to take Myfortic on an empty stomach. Take Myfortic two times daily: once in the morning and again 12 hours later in the evening. **Example:** Take a dose at 9am; take another dose at 9pm. Take the pills at the same time each day. If you miss a dose, take the next dose when it is scheduled. Do not take a double dose. What side effects Diarrhea can this drug Nausea, upset stomach, vomiting cause? A decrease in your white blood cell count and platelets An increased risk of infection. Do not crush, or split the tablets. Avoid touching the pill's powder. If you Is there anything else I should touch the powder wash your hands well with soap and water. know? Do not take any antacids (such as Maalox or Mylanta) at the same time you take Myfortic.



# Prednisone

 $(\textit{brand name: } Deltasone^{TM})$ 



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Why do I need to take this drug?	To prevent rejection	
How should I take this drug?	Prednisone comes in a variety of tablet sizes. Your doctor will decide the best dose for you.  Take prednisone in the morning with food.	
What side effects can this drug cause?	<ul> <li>Salt and water retention which can cause swelling and raise your blood pressure</li> <li>Acne</li> <li>Rounded face or chubby cheeks</li> <li>Increased desire to eat</li> <li>Weight gain</li> <li>Increased risk of stomach ulcers</li> <li>Mood changes</li> <li>Increased risk of sunburn</li> <li>Diabetes</li> <li>Eye problems, such as glaucoma or cataracts</li> <li>Softening of the bones with possible joint pain, especially in the hips</li> <li>Increased risk of infection</li> </ul>	
Is there anything else I should know?	Be sure to wear sunscreen with SPF of 30 or higher when outdoors.  Your doctor will decrease your dose of prednisone over time. Once you are on a lower dose, you probably will not suffer many side effects.  If you miss a dose take the dose later in the same day. If you realize that you missed a dose at night, do not take your dose and do not take an extra dose in the morning.	



#### **Sirolimus** $(\textit{brand name: } Rapamune^{TM})$ Why do I need to To prevent rejection take this drug? How should I take Rapamune comes in different strengths: this drug? 1 mg tablet 2 mg tablet Your doctor will decide the best dose for you. This medication is taken *once daily*. Most patients take this in the morning. If you are also taking cyclosporine (Neoral) you should take Rapamune at least 2 hours after you take cyclosporine. On clinic days, wait to take your morning dose until after you have your blood drawn. Do this even if it means that you will take your dose later than normal. Bring this medication to clinic with you. What side effects Slow wound healing can this drug A rise in cholesterol or triglyceride levels cause? A decrease in your white blood cell count or platelet count Anemia Constipation, diarrhea, nausea An increased risk of infection When taking this medicine avoid eating grapefruit or drinking grapefruit Is there anything else I should juice (including sodas with grapefruit – Fresca, Citrus Blast). know? If you miss a dose take it as soon as you can. If it is almost time for your

next dose do not take your missed dose. Do not take double or extra doses.



#### Valganciclovir $(\text{brand name: }Valcyte^{TM})$ Why do I need to To prevent viral infections, specifically cytomegalovirus (CMV) from take this drug? occurring. Valcyte comes as a 450 milligram tablet. How should I take this drug? Your dose will be based on your kidney function. What side effects A decrease in your white blood cell count or platelet count can this drug Nausea cause? Is there anything You will take this medication for 3 - 6 months after your transplant else I should know?



#### **Fluconazole** ROERIG $(\text{brand name: }Diflucan^{TM})$ Why do I need to To prevent fungal infections. take this drug? How should I take this drug? This medication is taken once daily What side effects Nausea, vomiting, diarrhea can this drug Rash, itching cause? You will take fluconazole for approximately 4 weeks after transplant. Is there anything else I should know?



# Sulfamethoxazole/Trimethoprim

(brand name: Bactrim<sup>TM</sup>)



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Why do I need to take this drug?	To prevent pneumocystis pneumonia (PCP) and most urinary tract infections.
How should I take this drug?	You will take one tablet every day or three times weekly, depending on kidney function.
What side effects can this drug cause?	<ul> <li>A decrease in your white blood cells</li> <li>Decreased kidney function</li> <li>Increased potassium level</li> <li>Increased sensitivity to the sun</li> <li>Rash</li> </ul>
Is there anything else I should know?	Do not take this medication if you are allergic to "sulfa" medications. You will take a different medication if you are allergic.  Be sure to wear sunscreen with SPF of 30 or higher when outdoors.  Drink plenty of water with this medication.



# <u>Famotidine</u>

 $(\text{brand name: } Pepcid^{TM})$ 



Why do I need to take this drug?	To prevent stomach ulcers and heartburn
How should I take this drug?	Famotidine comes in 20 milligram (mg) tablets. Take famotidine as often as your doctor says. The dose will depend on your kidney function.
What side effects can this drug cause?	<ul> <li>A decrease in your white blood cell count and platelet count</li> <li>Diarrhea or constipation</li> <li>Dizziness</li> <li>Headache</li> </ul>
Is there anything else I should know?	You can buy a lower dose of famotidine (10 mg) over the counter.  Patients usually stop taking famotidine about three months after transplant. But some patients need to take it longer.



# **Rejection**

Rejection is the natural reaction of your body to something new or foreign. The white blood cells of your body recognize that the cells of the transplanted organ are different. These white blood cells then increase in number and attack the cells of your transplanted organ.

Rejection is the biggest fear of a transplant patient. Most patients have at least one rejection episode. It is something that is expected and can be treated. The risk for rejection is highest during the first 3 months after transplant. But rejection can occur at any time, even years later. Fortunately, when recognized early, rejection is usually treatable.

The medicines you take control, stop or slow down the white blood cell's attack on the new organ. These immunosuppressants work to keep your body from rejecting the new organ. You must take your medication in the correct dosage and at the correct time. Missing even one dose increases your chance of rejection and losing your transplanted organ.

#### Signs of Rejection

- Temperature of 100 degrees or more
- Unusual fatigue or lack of energy/weakness
- Decreased urine output
- Increased weight gain (3 pound in 24 hours)
- Swelling and/or pain, tenderness at the incision
- Swelling of ankles/feet
- Elevated blood sugar (Pancreas)

Keeping your clinic appointments and having routine <u>lab work</u> is very important in monitoring for rejection. Many times, your lab work shows the Transplant Team concern for rejection BEFORE you *feel* anything!

#### **How to Prevent Rejection**

- Take your medication as prescribed and as scheduled
- Do NOT skip medication doses
- Complete all treatments for infections
- Discuss any new medication you are placed on with the transplant team.



# **Infections**

You are taking medications (immunosuppressants) to prevent rejection. These work by suppressing your immune system. This increases your risk of getting infections. The first sign of infection is often a fever.

Here are some other symptoms to look for and to report to the transplant team, nephrologist, or your primary care physician:



- Constant cough
- Burning feeling when you urinate
- Diarrhea
- Vomiting
- Sores in the mouth
- Rash or other skin changes.
- Redness or drainage from incision
- Elevated blood sugars

#### There are some simple things you can do to help prevent infection.

- Limit exposure to large crowds during your first three months post-transplant.
- Avoid contact with people who are sick.
- Wash fresh fruits and vegetables before eating and cooking.
- Call if you are exposed to measles, mumps, chicken pox, hepatitis, or any serious infectious disease.
- Avoid changing cat litter and cleaning bird cages.
- No gardening for the first six (6) months after six months, wear gloves and mask.



# **Incision Care**

Your abdominal incision is either stapled or glued. The staples will be removed 2-3 weeks after your surgery during your clinic visit. You may shower after your transplant; wash your incision with soap and water at least once a day. Please **DO NOT** take baths! After the shower you should pat the incision area dry with a towel. If there is no drainage, you can leave the incision open to air. There may be some drainage from the incision. If this happens, apply a clean dressing to protect your clothes. If it is soiled you may need to change the dressing up to every 4 hours.

## Observe your incision for any of the following:

- Redness
- Swelling
- Discolored drainage
- Foul smelling odor
- Incision separation
- Large amount of drainage (saturated dressing every four hours)

If you notice any of these signs please call your transplant team right away.





# **Hand washing**

One of the best ways to prevent catching an infection is to wash your hands often. Many infections are spread when you touch your mouth, nose or eyes with dirty fingers that are carrying germs. It is especially important to wash your hands:

- Before eating
- Before and after using the bathroom
- Before and after cleaning your surgical wound
- Before changing your contact lenses
- Before and after preparing food
- After shaking hands with a large number of people (for example, meeting or church service)
- After riding public transportation: a taxi, train or plane
- After grocery shopping

Hand sanitizers may also be used when soap and water are not available.

Any infection with a fever is worrisome and should be reported immediately to the transplant team, nephrologists, or your primary care physician.

Because you are more likely to get an infection, you must call the transplant team before having dental work or surgery. You may need antibiotics.

# Washing your hand is one of the most important parts of the plan to keep you healthy.

